



National Specialist Palliative Care Data Definitions Standard

HISO 10039.2

To be used in conjunction with HISO 10039.1 National Specialist Palliative Care Business Process Standard



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National Palliative Care Data Working Group

The National Palliative Care Data Working Group was responsible for providing technical advice for this document. Representatives from Northland, Canterbury, Auckland, Wellington, Hawkes Bay, MidCentral, Waikato, Hospice New Zealand and the Ministry of Health were involved in the Working Group.

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Programme representation

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Updates

Date	Version	Page number	Section number	Changes
December 2011	1.0			Published as 'Interim' Standard
June 2013	2.0			Changed status from 'Interim' Standard to 'Full' Standard

1 INTRODUCTION

The National Specialist Palliative Care Data Definition Standard is intended to ensure that minimum agreed specialist palliative care data is collected and stored in a consistent manner wherever it is collected and stored. The Standard encompasses and defines essential elements of service delivery. The associated business process document provides context for the data definition standard and describes the business processes involved in the collection and storage of palliative care data.

In doing so the specialist palliative care core data definition set will;

- provide a basis of a common language for discussions between stakeholders and for understanding palliative care in New Zealand
- · provide a framework for communication between information systems
- · be clear, simple and easy to use
- apply to local, regional and national levels
- · be adaptable and be able to be expanded
- align with national and international terminology

This standard defines the elements of palliative data that will be collected, stored and exchanged, providing an overview of each grouping of data items (e.g. name items), as well as:

- (a) a definition of each data item
- (b) attributes of each item, such as the maximum length of the field, the type of data it holds, the data domain (free text, code table, etc) and layout
- (c) information about the source of the defined element attributes
- (d) information such as guides for use, rules for verification
- (e) the following structure has been used in this document to record the attributes of each data item.

Definition:	A brief description of the data item.			
Source standards:	The source standa	ards from which the da	ata item was sourced or derived.	
Data type:Alphanumeric Alphabetic Numeric Date BooleanRepres class:		Representational class:	Text Number Date Y/N Code	
Field size:	number of characters available.		The way in which the contents of the field should be displayed. For example while the Data type might be "Alphanumeric" and the Field size might be "4", the Representational layout could be "ANN.N" where the "." is not saved as data.	
Obligation:	Mandatory, Condi	tional, Optional		
Data domain:	The source of the values that should be available for the data item.			
Guide for use:	A guide to the way in which this data item should be used.			
Verification rules:	A list of the rules governing collection and entry of values for the data item. This attribute should also record prerequisite conditions.			

Note: To ensure that the New Zealand context has been considered when replicating the Palliative Care Outcomes Collaboration (PCOC) codes, a number of the Version 2 codes have been retained while others have been updated to reflect the changes indicated in Version 3. The relevant PCOC version applied is noted under the 'Source standards' section in the tables.

Core Palliative Care Entities

The project used a high level business transaction process and information lifecycle model (Figure 1) to identify likely people, organisations, activities and data collection points involved in the palliative care pathway. As a result of this process, there are six principal entities and the relationship between those entities is shown below – each Patient will have one or more Episodes of Care and within each Episode of Care there will be one or more Service Contacts. Each Episode of care may also have one or more Diagnoses. Each Service Contact may have one or more Contact Purposes and one or more Provider Occupations.



Figure 1: Core Palliative Care Entities

2 PATIENT

The Patient entity contains details of each person receiving palliative care services.

The data elements for 'Patient' are:

1.	NHI Number
2.	Given Name
3.	Other Given Name(s)
4.	Family Name
5.	Date of Birth
6.	Sex
7.	Address Line 1
8.	Address Line 2
9.	Address Suburb
10.	Address City/Town
11.	Address Country/Region
12.	Postcode
13.	Ethnicity 1
14.	Ethnicity 2
15.	Ethnicity 3
16.	Ethnicity 4
17.	Ethnicity 5
18.	Ethnicity 6
19.	Place of Death
20.	Date of Death

2.1 NHI Number

Definition:	Unique 7-character identification number assigned to a healthcare user by the National Health Index (NHI) database.					
Source standards:	National Health	National Health Index Data Dictionary, v5.3, July 2009				
Data type:	Alphanumeric	Representational class:	Text			
Field size: 7		Representational layout:	AAANNNN			
Obligation:	Obligation: Mandatory					
Data domain:	Valid NHI number					
Guide for use: Primary key for this record, foreign key to related record(s) in the Episode of Care entity						
Verification rules:	Verification rules:					

2.2 Given Name

Definition:	The given name of a healthcare user.		
Source standards:			
Data type:	Alphabetic	Representational class:	Text
Field size:	40	Representational layout:	A(40)
Obligation:	Mandatory		
Data domain:			
Guide for use:	This data element should only be used for the 'given name' (or first name), but not the family name (surname).		
	The data element for 'Other Given [Middle] Name(s) should be used for second and subsequent names or initials, but not the family name (surname).		
Verification rules:			

2.3 Other Given Name(s)

Definition:	The patient's other given names and initials thereof at birth, but not the family name.			
Source standards:				
Data type:	Alphabetic	Representational class:	Text	
Field size:	40	Representational layout:	A(40)	
Obligation:	Optional			
Data domain:				
Guide for use:	The data element should only be used for patient's further given names or initials, but not their family name (surname). The patient's given name should be recorded under the data element Given Name (first name).			
	If a patient does not have any second or further given names, this field should be left blank. If there are multiple Other Given Names, separate each entry with a blank space.			
Verification rules:				

2.4 Family Name

Definition:	The family name (surname) of a healthcare user.			
Source standards:				
Data type:	Alphabetic	Representational class:	Text	
Field size:	50	Representational layout:	A(50)	
Obligation:	Mandatory			
Data domain:				
Guide for use:	Guide for use: This data element should be used for only the patient's surname, but <u>r</u> for their Given and further 'other given name(s)' or initials.			
	The content must preserve sentence case, for example: 'Maccall' is different from 'MacCall'.			
	The text entered can include one or more spaces, an apostrophe, and / or a hyphen eg, 'Van der Valk', O'Leary, 'Vaughn-Jones'.			
Verification rules:				

2.5 Date of Birth

Definition:	The date on which the person was born			
Source standards:				
Data type:	Date	Representational class:	Full date	
Field size:	8	Representational layout:	CCYY[MM[DD]]	
Obligation:	Mandatory			
Data domain:	Valid date			
Guide for use:	The full date of birth (year, month and day) must be recorded if known. Note: If not known, the month and day are conditional. The year of birth is mandatory			
Verification rules:				

2.6 Sex

Definition:	The person's biological sex				
Source standards:					
Data type:	Alphab	etic	Representational class:	Code	
Field size:	1 Representational layout: A				
Data domain:	Value Meaning				
	F	Female			
	I Indeterminate				
	М	M Male			
	U Unknown				
Obligation:	Mandatory				
Guide for use:					
Verification rules:					

2.7 Address Line 1

Definition:	The first line of the address at which a healthcare user has been, or plans to be, living at for 3 months or more. (Statistics NZ definition of 'usually resident'.)					
Source standards:						
Data type:	Alphanumeric Representational class: Text					
Field size:	30	30 Representational layout: A(30)				
Obligation:	Conditional. Mandatory if Address Line 2 is blank – otherwise optional					
Data domain:	Free text	Free text				
Guide for use:						
Verification rules:	Address Line 1	and Address Line 2 can not both	be blank			

2.8 Address Line 2

Definition:	The second line of the address at which a healthcare user has been, or plans to be, living at for 3 months or more. (Statistics NZ definition of 'usually resident'.)				
Source standards:					
Data type:	Alphanumeric Representational class: Text				
Field size:	30 Representational layout: A(30)				
Obligation:	Conditional. Mandatory if Address Line 1 is blank – otherwise optional				
Data domain:	Free text				
Guide for use:					
Verification rules:	Address Line 1 a	and Address Line 2 cannot both	be blank		

2.9 Address Suburb

Definition:	The third line of the address representing the suburb					
Source standards:						
Data type:	Alphanumeric	Representational class:	Text			
Field size:	30	30 Representational layout: A(30)				
Obligation:	Conditional. Mandatory if Address City/Town is blank – otherwise optional					
Data domain:	Free text	Free text				
Guide for use:						
Verification rules:	Address Suburb	and City/town cannot both be b	lank			

2.10 Address City/Town

Definition:	The fourth line of the address, representing the city, town or region. Either the third or the fourth line of the address is mandatory					
Source standards:						
Data type:	Alphanumeric Representational class: Text					
Field size:	30	30 Representational layout: A(30)				
Obligation:	Conditional. Mandatory if Address Suburb is blank – otherwise optional					
Data domain:	Free text					
Guide for use:						
Verification rules:	Address Suburb	and City/town cannot both be b	lank			

2.11 Address Country/Region

Definition:	The fifth line of the address, representing the external region or country			
Source standards:				
Data type:	Alphanumeric	Representational class:	Text	
Field size:	30	Representational layout:	A(30)	
Obligation:	Optional			
Data domain:	Free text			
Guide for use:				
Verification rules:				

2.12 Postcode

Definition:	The descriptor for a postal delivery area aligned with the locality, suburb or place for this address.				
Source standards:	HL7 2.5 2.A.1 A	D - address			
Data type:	Alphanumeric	Alphanumeric Representational class: Code			
Field size:	12 Representational layout: AN(12)				
Obligation:	Optional				
Data domain:	NZ Post postcode file International postcodes should be recorded as provided				
Guide for use:					
Verification rules:	Data for New Ze postcode file.	ealand postcodes should be verif	ied against the NZ Post		

2.13 Ethnicity 1

Definition:	Ethnicity is the ethnic group or groups that people identify with or feel they belong to. Ethnicity is a measure of cultural affiliation, as opposed to race, ancestry, nationality or citizenship. Ethnicity is self-perceived and people can belong to more than one ethnic group. An ethnic group is made up of people who have some or all of the following characteristics:				
	• a commo	on proper name			
		nore elements of o d, but may include		e that need not b	be
	 religion, 	customs, or langu	lage		
	 unique c 	community of inter	ests, feelings a	and actions	
	 a shared 	sense of commo	n origins or an	cestry, and	
	 a commethnic group 	on geographic ori roup.	gin. Māori in th	is report refers t	o the Māori
Source standards:	Ethnicity New Zealand Standard Classification 2005, ETHNIC05 V1.0, 01/06/2005				
Data type:	Numeric	Representation	al class:	Code	
Field size:	5 Representational layout: N(5)				
Obligation:	Conditional. Record if offered by patient.				
Data domain:	See the Ministry of Health's Ethnicity Data Protocols for the Health and Disability Sector at <u>http://www.health.govt.nz/publication/ethnicity-data-</u> protocols-health-and-disability-sector for a list of valid codes.				
Guide for use:	Ethnicity 1 should record the patient's first stated ethnicity. It is important to note that "first" does not refer to "preferred" – simply the first ethnicity offered by the patient. If the patient does not offer an ethnicity, record one of the following.				
		Code (Level 4)	Desc	ription	
		94444	Don't Know		-
		99999	Not Stated		
	95555 Refused to Answer				
	97777 Response Unidentifiable				
	Refer to Ethnicity Data Protocols for the Health and Disability Sector, Ministry of Health, 2004 for more guides to use.				

2.14 Ethnicity 2

Definition:	 Ethnicity is the ethnic group or groups that people identify with or feel they belong to. Ethnicity is a measure of cultural affiliation, as opposed to race, ancestry, nationality or citizenship. Ethnicity is self-perceived and people can belong to more than one ethnic group. An ethnic group is made up of people who have some or all of the following characteristics: a common proper name one or more elements of common culture that need not be specified, but may include religion, customs, or language unique community of interests, feelings and actions a shared sense of common origins or ancestry, and a common geographic origin. Māori in this report refers to the Māori ethnic group 			
Source standards:	Ethnicity New Zo 01/06/2005	ealand Standard Classification 2	005, ETHNIC05 V1.0,	
Data type:	Numeric	Representational class:	Code	
Field size:	5	Representational layout:	N(5)	
Obligation:	Conditional. Red	cord if second ethnicity offered b	y patient.	
Data domain:	See the Ministry of Health's Ethnicity Data Protocols for the Health and Disability Sector at http://www.health.govt.nz/publication/ethnicity-data-protocols-health-and-disability-sector for a list of valid codes.			
Guide for use:	Ethnicity 2 should record the patient's second stated ethnicity - the second ethnicity offered by the patient. Refer to <i>Ethnicity Data Protocols for the Health and Disability Sector</i> , Ministry of Health, 2004 for more guides to use.			
Verification rules:				

2.15 Ethnicity 3

Definition:	Ethnicity is the ethnic group or groups that people identify with or feel they belong to. Ethnicity is a measure of cultural affiliation, as opposed to race, ancestry, nationality or citizenship. Ethnicity is self-perceived and people can belong to more than one ethnic group. An ethnic group is made up of people who have some or all of the following characteristics:			
		on proper name nore elements of common culture	e that need not be	
	specified	d, but may include		
	-	customs, or language		
	•	community of interests, feelings a		
		d sense of common origins or an	•	
	 a common geographic origin. Māori in this report refers to the Māori ethnic group. 			
Source standards:	Ethnicity New Zo 01/06/2005	ealand Standard Classification 2	005, ETHNIC05 V1.0,	
Data type:	Numeric	Representational class:	Code	
Field size:	5	Representational layout:	N(5)	
Obligation:	Conditional. Red	cord if third ethnicity offered by p	atient.	
Data domain:	See the Ministry of Health's Ethnicity Data Protocols for the Health and Disability Sector at http://www.health.govt.nz/publication/ethnicity-data-protocols-health-and-disability-sector for a list of valid codes.			
Guide for use:	Ethnicity 3 should record the patient's third stated ethnicity - the third ethnicity offered by the patient.			
		ty Data Protocols for the Health a th, 2004 for more guides to use.	and Disability Sector,	
Verification rules:				

2.16 Ethnicity 4

Definition:	 Ethnicity is the ethnic group or groups that people identify with or feel they belong to. Ethnicity is a measure of cultural affiliation, as opposed to race, ancestry, nationality or citizenship. Ethnicity is self-perceived and people can belong to more than one ethnic group. An ethnic group is made up of people who have some or all of the following characteristics: a common proper name one or more elements of common culture that need not be specified, but may include religion, customs, or language 			
	 unique c 	community of interests, feelings a	and actions	
	 a shared 	d sense of common origins or an	cestry, and	
	 A common geographic origin. Māori in this report refers to the Māori ethnic group. 			
Source standards:	Ethnicity New Zo 01/06/2005	ealand Standard Classification 2	005, ETHNIC05 V1.0,	
Data type:	Numeric	Representational class:	Code	
Field size:	5	Representational layout:	N(5)	
Obligation:	Conditional. Rec	cord if fourth ethnicity offered by	patient.	
Data domain:	See the Ministry of Health's Ethnicity Data Protocols for the Health and Disability Sector at http://www.health.govt.nz/publication/ethnicity-data-protocols-health-and-disability-sector for a list of valid codes.			
Guide for use:	Ethnicity 4 should record the patient's fourth stated ethnicity - the fourth ethnicity offered by the patient.			
		ty Data Protocols for the Health a th, 2004 for more guides to use.	and Disability Sector,	
Verification rules:				

2.17 Ethnicity 5

Definition:	 Ethnicity is the ethnic group or groups that people identify with or feel they belong to. Ethnicity is a measure of cultural affiliation, as opposed to race, ancestry, nationality or citizenship. Ethnicity is self-perceived and people can belong to more than one ethnic group. An ethnic group is made up of people who have some or all of the following characteristics: a common proper name one or more elements of common culture that need not be specified, but may include religion, customs, or language unique community of interests, feelings and actions a shared sense of common origins or ancestry, and a common geographic origin. Māori in this report refers to the Māori ethnic group. 			
Source standards:	Ethnicity New Zo 01/06/2005	ealand Standard Classification 2	005, ETHNIC05 V1.0,	
Data type:	Numeric	Representational class:	Code	
Field size:	5	Representational layout:	N(5)	
Obligation:	Conditional. Red	cord if fifth ethnicity offered by pa	atient.	
Data domain:	See the Ministry of Health's Ethnicity Data Protocols for the Health and Disability Sector at http://www.health.govt.nz/publication/ethnicity-data-protocols-health-and-disability-sector for a list of valid codes.			
Guide for use:	Ethnicity 5 should record the patient's fifth stated ethnicity - the fifth ethnicity offered by the patient. Refer to <i>Ethnicity Data Protocols for the Health and Disability Sector</i> , Ministry of Health, 2004 for more guides to use.			
Verification rules:				

2.18 Ethnicity 6

Definition:	 Ethnicity is the ethnic group or groups that people identify with or feel they belong to. Ethnicity is a measure of cultural affiliation, as opposed to race, ancestry, nationality or citizenship. Ethnicity is self-perceived and people can belong to more than one ethnic group. An ethnic group is made up of people who have some or all of the following characteristics: a common proper name one or more elements of common culture that need not be specified, but may include religion, customs, or language unique community of interests, feelings and actions a shared sense of common origins or ancestry, and a common geographic origin. Māori in this report refers to the Māori ethnic group. 				
Source standards:	Ethnicity New Ze 01/06/2005	ealand Standard Classification 2	005, ETHNIC05 V1.0,		
Data type:	Numeric	Representational class:	Code		
Field size:	5	Representational layout:	N(5)		
Obligation:	Conditional. Rec	cord if sixth ethnicity offered by p	patient.		
Data domain:	See the Ministry of Health's Ethnicity Data Protocols for the Health and Disability Sector at http://www.health.govt.nz/publication/ethnicity-data-protocols-health-and-disability-sector for a list of valid codes.				
Guide for use:	ethnicity offered Refer to <i>Ethnicit</i>	Ethnicity 6 should record the patient's sixth stated ethnicity - the sixth ethnicity offered by the patient. Refer to <i>Ethnicity Data Protocols for the Health and Disability Sector</i> , Ministry of Health, 2004 for more guides to use.			
Verification rules:					

2.19 Place of Death

Definition:	The location of the patient at their death.				
Source standards:					
Data type:	Numeric		Representational class:	Code	
Field size:	3		Representational layout:	N(3)	
Obligation:	Conditiona	I. Red	cord if the patient is known to be	deceased	
Data domain:	Value Meaning				
	7	Correctional Facility			
	3	Hospice Inpatient Unit			
	4	Priva	ate Hospital		
	1	Priva	ate residence (including unit in re	tirement village)	
	5	Publ	ic Hospital		
	6	Resi	dential aged care, high level care	e (hospital level care)	
	2	Resi	dential aged care, low level care	(level 2 rest home)	
	99	Othe	r		
Guide for use:	Record if the patient is known to be deceased				
Verification rules:					

2.20 Date of Death

Definition:	The date on which the patient died. Sourced from Births, Deaths and Marriages.				
Source standards:	HL7 v2.4 DT – c	late			
Data type:	Date	Representational class:	Full date		
Field size:	8	8 Representational layout: CCYY[MM[DD]]			
Obligation:	Conditional. Record if the patient is known to be deceased and the date of death is known.				
Data domain:	Valid date				
Guide for use:	Must be on or after the Date of Birth, and before the current date. If diagnosed post mortem, the Date of Death is the Diagnosis Date.				
	The CCYY component of the date is mandatory (if known). MM is conditional (use if known). DD is conditional (use if known and MM has been recorded).				
Verification rules:	> Patient: Date	of Birth			

3 EPISODE OF CARE

An episode of care is a period of care when patients and their families receive services to improve their quality of life. Care of individual patients may occur in discrete episodes, which may be separated in time and location. Each episode of care will involve one or more service contacts.

The data elements for 'Episode of care' are:

1.	Episode ID
2.	NHI Number
3.	Referral Date
4.	Referral Source
5.	Episode Start Date
6.	Episode Start Accommodation
7.	Episode Start Support
8.	Proposed Model of Care
9.	Episode End Date
10.	Episode End Mode
11.	Episode End Accommodation
12.	Episode End Support

- 13. Provider Organisation
- 14. End of Life Care Plan Used
- 15. End of Life Care Plan

3.1 Episode ID

Definition:	Unique identifier for this record				
Source standards:					
Data type:	Numeric	Representational class:	numeric		
Field size:	11	Representational layout:	N(11)		
Obligation:	Mandatory				
Data domain:	Number				
Guide for use:	System generated primary key for this record				
Verification rules:					

3.2 NHI Number

Definition:	Unique 7-character identification number assigned to a healthcare user by the National Health Index (NHI) database.				
Source standards:	National Health	National Health Index Data Dictionary, v5.3, July 2009			
Data type:	Alphanumeric	Alphanumeric Representational class: Text			
Field size:	7 Representational layout: AAANNNN				
Obligation:	Mandatory				
Data domain:	Valid NHI number				
Guide for use:	Foreign key to related record in the Patient entity				
Verification rules:					

3.3 Referral Date

Definition:	The date the agency received a referral for this patient/client from another party for this episode of palliative care services.				
Source standards:	HL7 v2.4 DT - d	ate			
Data type:	Date	Date Representational class: Full date			
Field size:	8	Representational layout:	CCYYMMDD		
Obligation:	Optional				
Data domain:	Valid date				
Guide for use:	Time may elapse between the date the referral was received and the date it was accepted but it is the date the referral was received that should be recorded for this data item				
Verification rules:	Date of referral must be: > Patient: Date of Birth				

3.4 Referral Source

Definition:	Source of referral for this episode				
Source standards:		Palliative Care Outcomes Collaboration (PCOC), Australia, Version 2, 2006, Values from Version 3, 2012.			
Data type:	Numerio	0	Representational class:	Code	
Field size:	3		Representational layout:	N(3)	
Obligation:	Mandate	ory			
Data domain:	Value		Meaning		
	61	Comm	unity services (DHB based – Di	strict Community Nurse)	
	40	Genera	al Practice team		
	21 Hospice palliative care service				
	12	Māori I	Health Services		
	20 Private hospital				
	10 Public Hospital				
	71 Residential aged care, high level care (hospital level care)				
	70	Reside	ntial aged care, low level care (level 2 rest home)	
	80	Self, ca	arer(s), family, friends, whānau		
	50	Specia	list private medical practitioner		
	99	Other			
Guide for use:	If unsure of the employment of the General Practitioner (GP) as the referral source, select either 70 or 71 for Residential Aged Care (eg, visit by a GP at the request of a patient at a Residential Aged Care facility, or a GP employed by a Residential Aged Care facility).				
Verification rules:					

3.5 Episode Start Date

Definition:	Episode Start Date is the date of the first interaction between this agency and the patient/client. If after assessment the patient is not deemed to be suitable for palliative care services in this agency, the assessment will be recorded as a Service Contact and the Episode will end.			
Source standards:	Palliative Care C	Outcomes Collaboration (PCOC)	, Australia, Version 3, 2012	
Data type:	Date	Representational class:	Full date	
Field size:	8	Representational layout:	CCYYMMDD	
Obligation:	Mandatory			
Data domain:	Valid date			
Guide for use:				
Verification rules:	Episode start date must be:			
	>= Episode of Care: Date of Referral			
	>= Patient:Date of Birth			
	<= Patient:Date of Death			

3.6 Episode Start Accommodation

Definition:	Type of usual accommodation at the commencement of the episode				
Source standards:	Palliative	e Care C	Outcomes Collaboration (PCOC)	, Australia, Version 3, 2012	
Data type:	Numeric		Representational class:	Code	
Field size:	3		Representational layout:	N(3)	
Obligation:	Mandato	ory			
Data domain:	Value Meaning 1 Private residence (including unit in retirement village)				
	2	evel 2 rest home)			
	3	Residential aged care, high level care (hospital level care)			
	4	Correc	Correctional facility		
	5	Public	hospital		
	6	Hospic	e Inpatient Unit		
	99	99 Other			
Guide for use:	Implementation guide: Choosing options 2 or 3 of Episode Start Accommodation should result in options 1, 2, and 3 of Episode Start Support being unavailable.				
Verification rules:					

3.7 Episode Start Support

Definition:	Level of support received at the commencement of the episode				
Source standards:	Palliative Care Outcomes Collaboration (PCOC), Australia, Version 2, 2006				
Data type:	Numeric	Representational cla	ass:	Code	
Field size:	3	Representational lay	out:	N(3)	
Obligation:	Mandatory				
Data domain:	Value Meaning				
	1	Lives alone with no care	e/support	provided	
	2	Lives with others with n	o care/su	pport provided	
	3	Lives alone with externa	al profess	ional support	
	4	Lives with others who p	rovide ca	re/support	
	5	Lives with others with e	xternal pr	ofessional support	
	6	Other arrangements			
	99	Not stated/inadequately	/ describe	d/not applicable	
Guide for use:					
	Value and Meaning G			r Use	
	3 "Lives alone professional su			no live alone but receive professional support.	
	4 "Lives with o care/support"		Those who live in the company of others and rely on them for care or support.		
	4. Lives with others who provide care/support.A patient at the sta should h 			atient living in residential care le start of this episode of care uld have this data element rd as 4	
				no live in the company of t do not rely on them for upport. In this instance, ort received is external nal support.	
	Implementation guide: Choosing options 2 or 3 of Episode Start Accommodation should result in options 1, 2, and 3 of Episode Start Support being unavailable				
Verification rules:					

3.8 Proposed Model of Care

Definition:	The type of care planned at the start of this episode of care					
Source standards:	Palliati	Palliative Care Outcomes Collaboration (PCOC), Australia, Version 2, 2006				
Data type:	Numer	Numeric Representational class: Code				
Field size:	3		Representational layout:	N(3)		
Obligation:	Mandatory					
Data domain:	Value Meaning					
	1 Sole care. The provider is the primary provider and has responsibility for the provision of care.					
	2 Shared care with another service provider(s) (cancer care, respiratory, GP, MND, community health)					
	3 Consultation/liaison with another service provider					
Guide for use:	The model of care may change during the episode but this data item is intended to reflect the type of care planned at the start of the episode.					
Verification rules:						

3.9 Episode End Date

Definition:	The date of episode end				
Source standards:	Palliative Care Outcomes Collaboration (PCOC), Australia, Version 3, 2012				
Data type:	Date Representational class: Full date				
Field size:	8	Representational layout:	CCYYMMDD		
Obligation:	Optional				
Data domain:	Valid date – the date of discharge or transfer or the date of death where grief or bereavement counselling is not immediately required. If grief or bereavement counselling is subsequently identified a new episode of care will need to be established.				
Guide for use:	It is important that Episode End Date is recorded in the same way wherever it is recorded. For that reason, Episode End Date should be recorded as the later of Date of Discharge, Date of Transfer, Date of Death (where grief or bereavement counselling is not immediately required). Services provided after a patient's death (e.g. grief counselling) should be recorded within a new Episode of Care where they have been provided action of the second state.				
	some time after a patient's death. Where the Episode of Care was started after the patient's death, the Episode End Date should be recorded as the date of the last Service Contact for that Episode of Care.				
Verification rules:	>= Episode of Ca	re: Episode Start Date			

3.10 Episode End Mode

Definition:	How this episode ended.					
Source standards:	Palliative	Palliative Care Outcomes Collaboration (PCOC), Australia, Version 3, 2012				
Data type:	Numeric		Representational class:	Code		
Field size:	3		Representational layout:	N(3)		
Obligation:	Conditional – mandatory if Episode End Date present					
Data domain:	Value	ue Meaning				
	11	11 Discharged				
	13	3 Deceased				
	14	Transferred to other palliative care service				
	99	99 Other				
Guide for use:		Implementation guide: Choosing option 13 should result in all options of Episode End Accommodation being unavailable.				
Verification rules:						

3.11 Episode End Accommodation

Definition:	Type of usual accommodation at episode end.					
Source standards:	Palliative	Palliative Care Outcomes Collaboration (PCOC), Australia, Version 3, 2012				
Data type:	Numeric		Representational class:	Code		
Field size:	3		Representational layout:	N(3)		
Obligation:	Condition	Conditional – mandatory if Episode End Date present				
Data domain:	Value Meaning					
	1	Private	e residence (including unit in retir	rement village)		
	2	Reside	ential aged care, low level care (I	evel 2 rest home)		
	3	Reside	ential aged care, high level care	(hospital level care)		
	4	Correc	tional facility			
	99	Other				
Guide for use:	Implementation guide: Choosing options 2 or 3 of Episode End Accommodation should result in options 1, 2, and 3 of Episode End Support being unavailable.					
Verification rules:						

3.12 Episode End Support

Definition:	Level of support received at episode end.				
Source standards:	Palliative	Care C	Outcomes Collaboratio	on (PCOC)	, Australia, Version 2, 2006
Data type:	Numeric		Representational c	lass:	Code
Field size:	3		Representational la	ayout:	N(3)
Obligation:	Condition	nal – ma	andatory if Episode Er	nd Date pre	esent
Data domain:	Value			Meaning	
	1	Lives	alone with no care/su	pport provi	ided
	2	Lives	with others with no ca	are/support	provided
	3	_	alone with external su	• •	
	4	_	with others who provi		
	5	_	with others with exter	nal suppor	t
	6	_	arrangements		
	99	Not st	ated/inadequately dea	scribed/not	applicable
Guide for use:					
	Value a	nd Mea	aning	Guide for Use	
	3 "Lives professi		with external ipport"	Those who live alone but receive external professional support.	
	4 "Lives with others who provide care/support"				no live in the company of id rely on them for care or
	4. Lives with others who provide care/support.A patient living in residential care at the start of this episode of care should have this data element record as 4			rt of this episode of care ave this data element	
	professional support" others but do not r care or support. In			no live in the company of it do not rely on them for upport. In this instance, ort received is external nal support.	
	Implementation guide: Choosing options 2 or 3 of Episode End Accommodation should result in options 1, 2, and 3 of Episode End Support being unavailable.				
Verification rules:					

3.13 Provider Organisation

Definition:	A code that uniquely identifies a healthcare facility. A healthcare facility is a place, which may be a permanent, temporary, or mobile structure that healthcare users attend or are resident in for the primary purpose of receiving healthcare or disability support services. This definition excludes supervised hostels, halfway houses, staff residences, and rest homes where the rest home is the patient's usual place of residence.				
Source standards:	N/A				
Data type:	Alphanumeric	Alphanumeric Representational class: Code			
Field size:	6 Representational layout: FXXNNN				
Obligation:	Mandatory				
Data domain:	Validated against the Health Practitioner Index (HPI) Data Set				
Guide for use:	F is a constant prefix. X is either an alpha or a numeric. The Facility Identifier is assigned by the HPI system at the time that the facility record in the HPI is created.				
Verification rules:					

3.14 End of Life Care Plan Used

Definition:	Indicates whether an End of Life care plan was used			
Source standards:	N/A			
Data type:	Boolean	Representational class:	N/A	
Field size:	1	Representational layout:	Y/N	
Obligation:	Mandatory			
Data domain:				
Guide for use:	Y (Yes/True) if an End of Life Care Plan was used			
	N (No/False) if an End of Life Care Plan was not used			
Verification rules:				

3.15 End of Life Care Plan

Definition:	Name and/or description of the End of Life care plan used					
Source standards:						
Data type:	Numeric		Representational class:	Code		
Field size:	3		Representational layout:	N(3)		
Obligation:	Mandato	Mandatory if "End of Life Care Plan Used" is set to Yes/True				
Data domain:	Value Meaning					
	1 Liverpool care pathway for the dying NZ adaptation http://www.lcpnz.org.nz/pages/home/					
				Z adaptation		
				Z adaptation		
Guide for use:	99	http://w Other		· · · · · · · · · · · · · · · · · · ·		

4 SERVICE CONTACT

Service contacts are services that are provided to, or on behalf of, the patient and/or their carer(s)/family/friends, or whānau that result in a dated entry being made in the client record, except where the service is primarily of an administrative nature (for example, making an appointment on behalf of a client). A palliative care client may receive more than one service contact per day, and may receive different types of assistance within one service contact. The types of care provided at a service contact may, for example, include medical care, nursing care and spiritual care. It is not intended that the burden of collection exceeds the value of collection, so record only those contacts that have value as part the clinical and service record.

The data elements for 'Service contact' are:

- 1. Service Contact ID
- 2. Episode ID
- 3. Service Contact Start Date
- 4. Recipient Type
- 5. Delivery Setting
- 6. Contact Method
- 7. Service Contact End Date
- 4.1 Service Contact ID

Definition:	Unique identifier for this record				
Source standards:					
Data type:	Numeric	Representational class:	Number		
Field size:	11	Representational layout:	N(11)		
Obligation:	Mandatory	Mandatory			
Data domain:	Number				
Guide for use:	System generated primary key for this record				
Verification rules:					

4.2 Episode ID

Definition:	The identifier for the episode of care record to which this service contact relates			
Source standards:				
Data type:	Numeric	Representational class:	Number	
Field size:	11	Representational layout:	N(11)	
Obligation:	Mandatory			
Data domain:	Number			
Guide for use:	Foreign key to related record in the Episode of Care entity			
Verification rules:				

4.3 Service Contact Start Date

Definition:	The date the contact started				
Source standards:	Australian Institu	Australian Institute of Health and Welfare (AIHW), Australia, 2007			
Data type:	Date	Date Representational class: Full date			
Field size:	8	Representational layout:	CCYYMMDD		
Obligation:	Mandatory				
Data domain:	Valid date				
Guide for use:					
Verification rules:	This field must be:				
	>= Episode of Care: Episode Start Date, and				
	<= Episode of Ca	<= Episode of Care: Episode End Date			

4.4 Recipient Type

Definition:	Categorisation of the recipient. It is not only the patient who may receive a service in this context				
Source standards:	Australiar	n Institu	ute of Health and Welfare (AIHW), Australia, 2007	
Data type:	Numeric		Representational class:	Code	
Field size:	3		Representational layout:	N(3)	
Obligation:	Mandator	У	· · · · · · · · · · · · · · · · · · ·		
Data domain:	Value Meaning				
	1	Patier	nt		
	2	Patier	nt and carer(s), family, friends, w	hānau	
	3	Carer	(s), family, friends, whānau		
	4	Other	professional(s)/service provider	(s) only	
	5	Other	recipient		
	99	Unkn	own		
Guide for use:	Where one care provider interacts with another regarding the care of a patient, 4 "Other professional(s)/service provider(s) only" should be selected as the Recipient Type				
Verification rules:					

4.5 Delivery Setting

Definition:	The setting in which the service contact took place.				
Source standards:	Australia	n Institu	ute of Health and Welfare (AIHW	/), Australia, 2007	
Data type:	Numeric		Representational class:	Code	
Field size:	3		Representational layout:	N(3)	
Obligation:	Mandato	ſy		·	
Data domain:	Value		Meaning		
	12	Day A	ctivities programmes		
	11	Corre	ctional Facility		
	3	Hospi	ce inpatient unit		
	4	Hospi	ce outpatient clinic		
	7	Not a	Not applicable (patient/client not present at service contact)		
	6	Privat	Private hospital inpatient unit		
	9 Privat		Private hospital outpatient clinic		
	1	Privat	Private residence		
	5	Public	c hospital inpatient unit		
	8	Public	c hospital outpatient clinic		
	10	Resid	ential aged care, high level care	e (hospital level care)	
	2	Resid	ential aged care, low level care	(level 2 rest home)	
	99	Other			
Guide for use:	Where one care provider interacts with another regarding the care of a patient other than with the patient, select 7 "Not applicable (patient/ client not present at service contact)"				
Verification rules:					

4.6 Contact Method

Definition:	The way in which the service contact took place			
Source standards:	Australian	Institu	ite of Health and Welfare (AIHW), Australia, 2007
Data type:	Numeric		Representational class:	Code
Field size:	3		Representational layout:	N(3)
Obligation:	Mandatory			
Data domain:	Value	Value Meaning		
	1	Face-	to-face	
	2	Telep	hone	
	3	Writte	n (including email, txt)	
	4	Tele/\	video/web conference	
	99 Other			
Guide for use:				
Verification rules:				

4.7 Service Contact End Date

Definition:	The date the contact ended			
Source standards:	Australian Institu	ute of Health and Welfare (AIHW), Australia, 2007	
Data type:	Date	Representational class:	Full date	
Field size:	8	Representational layout:	CCYYMMDD	
Obligation:	Optional			
Data domain:	Valid date			
Guide for use:				
Verification rules:	This field must be:			
	>= Episode of Care: Episode Start Date, and <= Episode of Care: Episode End Date			

5 DIAGNOSIS

The data record Diagnosis contains details of diagnoses. It should include the principal diagnosis and any clinically relevant additional diagnoses.

The data elements for 'Diagnosis' are:

- 1. Diagnosis ID
- 2. Episode ID
- 3. Diagnosis
- 4. Principal Diagnosis

5.1 Diagnosis ID

Definition:	Unique identifier for this record				
Source standards:					
Data type:	Numeric	Representational class:	Number		
Field size:	11	Representational layout:	N(11)		
Obligation:	Mandatory				
Data domain:	Number				
Guide for use:	System generated primary key for this record				
Verification rules:					

5.2 Episode ID

Definition:	The identifier for the episode of care record to which this diagnosis relates				
Source standards:					
Data type:	Numeric	Representational class:	Number		
Field size:	11	Representational layout:	N(11)		
Obligation:	Mandatory				
Data domain:	Number				
Guide for use:	Foreign key to related record in the Episode of Care entity				
Verification rules:					

5.3 Diagnosis

Definition:	A diagnosis clinically relevant to the patient's care. The Principal Diagnosis field indicates whether this diagnosis is the principal diagnosis or an additional diagnosis.			
Source standards:	Palliative Care Outcomes Collaboration (PCOC), Australia, Version 3, 2012			
Data type:	Numeric	Representational class:	Code	
Field size:	3	Representational layout:	N(3)	
Obligation:	Mandatory			
Data domain:	Value	Meani	ng	
	206	Alzheimer's Dementia		
	101	Cancer - Bone and Soft Tissue		
	102	Cancer - Breast		
	103	Cancer – CNS		
	104	Cancer - Colorectal		
	112	Cancer - Gynaecological		
	106	Cancer - Haematological		
	107	Cancer - Head and Neck		
	108	Cancer – Lung		
	113	Cancer - Melanoma / Skin		
	105	Cancer - Other GIT		
	180	Cancer - Other Primary Malignancy		
	111	Cancer - Other Urological Malignancy		
	109	Cancer - Pancreas		
	110	Cancer - Prostate		
	114	Cancer - Unknown Primary		
	201	Cardiovascular Disease		
	211	Diabetes and its complications		
	203	End Stage Kidney Disease (Re	nal Disease)	
	210	End Stage Liver Disease (Hepa	atic disease)	
	202	HIV/AIDS	,	
	100	Malignant – not further defined		
	205	Motor Neurone Disease		
	213	Multi-organ Failure		
	200	Non Malignant – not further def	fined	
	207	Other Dementia		
	208	Other Neurological Disease		
	280	Other non-malignancy		
	209	Respiratory Disease		
	212	Sepsis		
	204	Stroke		
	999	Unknown		
Guide for use:	There is no need to record an ICD-10 or SNOMED-CT code for diagnosis in this data specification. Should there be a need, these classifications can be mapped to either ICD-10 or SNOMED-CT at a later date.			
Verification rules:				

5.4 Principal Diagnosis

Definition:	Indicates whether a diagnosis was the principal diagnosis. The Principal Diagnosis is the broad diagnostic group established after study to be mainly responsible for occasioning the patient's episode of care				
Source standards:	N/A				
Data type:	Boolean	Representational class:	N/A		
Field size:	1	Representational layout:	Y/N		
Obligation:	Mandatory				
Data domain:					
Guide for use:	Yes (Y) if the diagnosis was the principal diagnosis No (N) if the diagnosis was an additional diagnosis.				
Verification rules:					

6 CONTACT PURPOSE

The data record Contact Purpose contains the purpose descriptions applicable to the related Service Contact record.

The data elements for 'Contact Purpose' are:

- 1. Contact Purpose ID
- 2. Service Contact ID
- 3. Contact Purpose

6.1 Contact Purpose ID

Definition:	Unique identifier for this record			
Source standards:				
Data type:	Numeric	Representational class:	Number	
Field size:	11	Representational layout:	N(11)	
Obligation:	Mandatory			
Data domain:	Number			
Guide for use:	System generated primary key for this record			
Verification rules:				

6.2 Service Contact ID

Definition:	The identifier for Service Contact record to which this Contact Purpose relates				
Source standards:					
Data type:	Numeric	Representational class:	Number		
Field size:	11	Representational layout:	N(11)		
Obligation:	Mandatory				
Data domain:	Number				
Guide for use:	Foreign key to related record in the Service Contact entity				
Verification rules:					

6.3 Contact Purpose

Definition:	The purpose of the Service Contact record to which this Contact Purpose record relates				
Source standards:	Australian	Institu	ite of Health and Welfare (AIHW	/), Australia, 2007	
Data type:	Numeric		Representational class:	Code	
Field size:	3		Representational layout:	N(3)	
Obligation:	Mandator	y		I	
Data domain:	Value		Meaning		
	3	Cas	e management and/or care coor	rdination	
	2	Clin	ical care		
	1	Con	prehensive assessment		
	18	Day	activities programmes		
	12	Edu	cation of the patient and family/v	whānau	
	13	Fam	ily/ whānau meeting		
	9 Grief and loss support				
	14	Inpatient admission			
	16	Inpa	Inpatient discharge		
	15 Mult		Multi-disciplinary review		
	5 Pers		Personal care		
	10	Psy	Psycho-emotional support		
	6	Soc	Social support Spiritual care or support		
	4	Spir			
	98	Othe	er		
	99	Not	stated		
Guide for use:	Implementation of this data item should permit multiple items to be selected where the visit has more than one purpose.				
	Where a family meeting has taken place and multiple providers were present, record as one service contact (with multiple providers recorded) A multi-disciplinary meeting should not be assumed as having taken place when a Comprehensive assessment is selected. Record both explicitly. Refer to Appendix B – Contact Purpose for more detail of each of the values in this data domain.				
Verification rules:					

7 PROVIDER OCCUPATION

The data record Provider Occupation contains the occupation descriptions of the providers who participated in the related Service Contact record.

The data elements for 'Provider Occupation' are:

- 1. Provider Occupation ID
- 2. Service Contact ID
- 3. Provider Occupation
- 7.1 Provider Occupation ID

Definition:	Unique identifier for this record				
Source standards:					
Data type:	Numeric	Representational class:	Number		
Field size:	11	Representational layout:	N(11)		
Obligation:	Mandatory				
Data domain:	Number				
Guide for use:	System generated primary key for this record				
Verification rules:					

7.2 Service Contact ID

Definition:	The identifier for the Service Contact record to which this Provider Occupation record relates				
Source standards:					
Data type:	Numeric	Representational class:	Number		
Field size:	11	Representational layout:	N(11)		
Obligation:	Mandatory				
Data domain:	Number				
Guide for use:	Foreign key to related record in the Service Contact entity				
Verification rules:					

7.3 Provider Occupation

Definition:	The occupation of the Service Contact provider				
Source standards:	Australian Institute of Health and Welfare (AIHW), Australia, 2007				
Data type:	Numeric		Representational class:	Code	
Field size:	3		Representational layout:	N(3)	
Obligation:	Mandatory				
Data domain:	Value Meaning				
	19	Com	plementary therapist		
	12	12 Dietician			
	6 Grief/Bereavement counsellor				
	14 Māori health worker				
	1 Medical practitioner				
	3 Nurse				
	20 Nurse practitioner				
	9				
	16	16 Other counsellor			
	15 Personal care assistant/nurse assistant/ health care assistant				
	18 Pharmacist				
	8 Physiotherapist				
	13 Podiatrist				
	7	7 Psychologist			
	11	Social worker			
	10	10 Speech therapist			
	5 Spiritual carer				
	17	Volu	nteer		
	99	Othe	er occupation		
Guide for use:	Implementation of this data item should permit multiple items to be selected where more than one provider is involved in the Service Contact.				
	Where one care provider interacts with another regarding the care of a patient, 4 "Other professional(s)/service provider(s) only" should be selected as the Service Contact: Recipient Type				
Verification rules:					

APPENDIX A – GLOSSARY

Term	Description
AIHW	Australian Institute of Health and Welfare
METeOR	An application maintained by the Australian Institute of Health and Welfare where metadata is stored, managed and disseminated.
NHI	National Health Index – unique identifier for NZ health care users
PCOC	Palliative Care Outcomes Collaboration

APPENDIX B – CONTACT PURPOSE

Value	Meaning
1	<u>Comprehensive assessment</u> The needs, strengths, understandings and expectations of the patient, their caregiver/s and family/whānau are documented and reflected upon in the assessment. This incorporates the physical, spiritual, social and emotional parameters. Services that are appropriate to the level/needs of care for the patient/family/whānau are offered and explained.
2	Clinical care The provision of medical and nursing care according to the assessed care requirements of the patient.
3	Case management and/or care coordination Includes, but not limited to, case conference activities or discussion/review of a case between two or more service providers, liaison with, and referral to other service providers, and communication with patient and/or family/whānau.
4	Spiritual care or support Refers to attending to spiritual matters of patient and family/whānau including but not limited to beliefs, meaning, identity and hope.
5	Personal care Refers to assistance with daily self-care tasks such as but not limited to eating, bathing, toileting and grooming, transferring in and out of bed
6	Social support Refers to the assessment, discussion and/or liaison with other services in order to address matters including but not limited to income, benefits, home help eligibility, and the enabling of independence of the patient or family/whānau.
9	Grief and loss support Emotional and spiritual support focussed on loss and grief includes the patient, the caregiver/s and family/whānau. This may begin when a life limiting illness is diagnosed. On-going support based on self-identified need is offered to the caregiver/s and family.
10	<u>Psycho-emotional support</u> Concerned with the psychological and emotional well-being of the patient and their family/whānau including, but not limited to issues of self-esteem, insight into and adaption to illness and its consequences, communication and impact on social functioning.
12	Education of the patient and family/whānau Education going beyond the normal procedural explanations given to patients and their families. Should encompass the determination of what the patients and their families wish to learn.
13	<u>Family/whānau meeting</u> Where family/ whānau as defined by the patient are invited to discuss with members of the MDT, their understanding and concerns that relate to the preceding or current clinical events, and/or the planning care needs with the expected course of the patient in mind.
14	Inpatient admission The admission of a patient to an inpatient specialist palliative care inpatient unit.
15	<u>Multi-disciplinary review</u> The appraisal of a patient's comprehensive assessment by the Multi-disciplinary team in order to develop a holistic approach to the management options available to the patient and family/whānau.
16	Inpatient discharge The discharge of a patient from a specialist palliative care inpatient unit.
18	<u>Day Activities Programme</u> The attendance of a patient at a Hospice/specialist palliative care day programme that may include, but not be limited to focused activities for maintaining independence, promoting well-being, providing information, therapeutic or respite care (non clinical/medical programmes).
98	Other

Value	Meaning
	Any contact purpose other than those listed in this table.
99	Not stated